

Chronic fatigue syndrome: sufferers' evaluation of medical support

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SUMMARY

In response to reports of negative cooperation between sufferers of chronic fatigue syndrome (CFS) and their doctors, semi-structured interviews were conducted with sufferers from two different patient samples.

Satisfaction with support received and with medical professionals in general was low. Sufferers complained about insufficient informational as well as emotional support from their doctors, and as a consequence most opted for alternative or complementary forms of treatment. In addition, disagreements over illness aetiology and treatment precluded effective cooperation.

If satisfaction and compliance are to improve, sufferers will need more information about CFS and more support.

INTRODUCTION

The chronic fatigue syndrome (CFS), also called post-viral fatigue syndrome (PVFS) and myalgic encephalomyelitis (ME), is characterized by severe fatigue after minimal effort, myalgia, headache, sensitivity to light and noise, cognitive difficulties, and frequently, depression^{1,2}. The illness duration seems to vary, some sufferers recovering after one year while others claim to have been afflicted for 20 or more years^{3,4}.

Although its aetiology remains unknown, evidence points to psychiatric disorder, precipitation by viral infection, and immune dysfunction⁵⁻⁷. Most researchers now accept the interaction of several biological, social, and psychological factors⁸⁻¹¹. Because of the uncertainty surrounding its aetiology and because of the heterogeneous symptomatology, CFS is difficult to diagnose, but diagnostic research criteria have now been developed¹².

Antidepressants have featured in the treatment of CFS and cognitive behaviour therapy has become more prominent^{4,13}. Unlike health professionals, however, most sufferers hold on to a view of CFS as a purely or predominantly physical disease caused by viral infection, and they are therefore reluctant to receive psychiatric or psychological help^{14,15}. In addition, at present there is not enough evidence to conclude that antidepressants or cognitive behaviour therapy are effective in reducing the symptoms of CFS. The rejection of psychiatric help, combined with the little assistance medical treatment has offered so far, has led sufferers to turn increasingly to

complementary and alternative medicine. While certain forms of complementary medicine and possibly some forms of alternative medicine, such as acupuncture, can be helpful in alleviating the symptoms of CFS, many sufferers spend a large proportion of their financial resources on therapies for which there is no or little scientific support, including anti-candida treatment, dental amalgam removal, signalysis therapy, colonic irrigation, dowsing, and spiritual healing³. Overall, the lack of a known aetiology for CFS, its uncertain prognosis, increasing disability, and the unavailability of an effective form of treatment often lead to sufferers' desperate attempts at finding a cure, no matter what.

This search for help outside the orthodox medical establishment could, however, also contribute to deficiencies in the doctor and sufferer interaction. In fact, several sources have described the lack of effective communication between physicians and CFS sufferers^{3,4,15}. These reports show that physicians often have difficulty in diagnosing CFS because of uncertainties surrounding the origin and symptomatology and, in view of the multiplicity of treatment approaches, tend to be uncertain about the most effective type of treatment. Sufferers, on the other hand, are usually anxious about their symptoms and expect a firm diagnosis as well as an effective treatment or cure. In these circumstances the physician cannot meet the sufferer's expectations.

Ley¹⁶ argues that patients' satisfaction with the medical consultation, as well as their understanding of its content and recall of information, determines compliance with the treatment offered. According to him the factors that determine patients' satisfaction with their consultation are its affective aspects (e.g. emotional support) and its

behavioural aspects (e.g. prescribing and explaining) and the doctor's competence (e.g. diagnosis). In CFS information about the illness is especially important because most patients lack medical knowledge and understanding of illness¹⁷ and many are resistant to aetiological explanations other than initial or ongoing viral infection. This paper, based on sufferers' accounts, describes ways in which physicians and sufferers communicated, sufferers' cognitions and illness beliefs which form the basis of their treatment expectations, and the consequences of such interactions in terms of sufferers' future treatment choices.

METHOD

This report is based on two separate studies which were part of a larger project on illness adjustment. In both studies, participants were recruited from several London-based ME support groups. A general requirement for participation was diagnosis of ME, CFS, or PVFS by a medical practitioner. In study 1 there were 9 participants, 6 female. Their mean age was 44.22 years (SD 5.21), range 16–68 years. Their mean illness duration was 7.89 years, range 1–14 years. 4 of these sufferers were employed full-time, 1 worked part-time and another went to school part-time, 1 had given up work completely as a result of CFS, and 1 had retired. In study 2 there were nine sufferers, 8 women. The mean age was 44.5 years (SD 7.67), range 34–55 years. The mean illness duration was 7.7 years, 1–19 years. None of these sufferers worked, but one attended college one day a week.

These participants were interviewed at home (SA). Confidentiality and the voluntary nature of the study were stressed. The interview was semi-structured and covered issues concerning adaptation to CFS and support received. The latter included questions about the doctor-sufferer relationship before and after diagnosis, satisfaction with the treatment received, and about sufferers' views on their doctors and the health service.

The interviews, which lasted about 90 minutes, were tape-recorded and later transcribed. The data were analysed by content analysis. The quotations below reflect the desire of most of the sufferers to use the term ME rather than CFS.

RESULTS

Illness beliefs

Pre-diagnosis

For some the onset of CFS was gradual ($n=11$); for others it was sudden ($n=7$). As a consequence sufferers attributed their symptoms to different causes. 4 feared that they had multiple sclerosis, 2 thought they had a brain tumour, 2 believed they had some sort of allergy, 2 thought they had cancer, and the remainder believed that they had contracted

influenza. Those who feared that the symptoms were a result of a malignant disease reported extreme anxiety that was relieved only by negative test results. A diagnosis of depression was initially considered by some of the practitioners treating sufferers in the present sample, and 3 had previously been diagnosed as depressed. However, sufferers firmly rejected depressive illness as the cause of their symptoms. For example, one said:

I've had depression before, sort of not very badly, but I've been depressed enough to sort of, you know, to be sent to a psychiatrist and put on antidepressants . . . And for me it was nothing like that. It was very clearly a physical disability . . . I could say definitely I wasn't depressed. I got miserable at times because it's miserable being in that situation.

Those who suffered for several years without being diagnosed eventually suspected CFS after hearing about it through friends and the media, and asked their doctors to be tested for CFS. Several doctors, however, initially rejected CFS and insisted on depression, a response that made the sufferers angry.

Post-diagnosis

Once the diagnosis was made, sufferers attributed the CFS to an ongoing or initial viral infection with resulting immune dysfunction, psychological stress with resulting immune dysfunction, or environmental stress with resulting immune dysfunction. Psychological stress included work-related stress, hyperactive children, divorce, adultery, and bereavement. Environmental stress was described as mercury fillings, pollution, and energy sources in the home. The following statements illustrate these illness attributions:

I think it's a virus . . . And what I explained to the doctor was that there was the feeling that there was a virus in my body that was dormant for, you know, a good bit of the time, and then all of a sudden would come out to the fore, and come to the surface every now and then.

Looking back at people's lives, there's a pattern of stress. And certainly looking back at mine I think there was always an onslaught on my immune system. I was quite a sickly child . . . And I'm sure the fact that I was never particularly happy, I was always under some sort of stress, almost fearful of something . . . That cannot have improved my resistance.

Meaning of the diagnosis and satisfaction with perceived medical support

CFS was generally diagnosed by the sufferers' GP. For most sufferers the diagnosis was a relief because finally a name had been given to their symptoms. They knew then it was not a life-threatening illness and had a label:

It [diagnosis] made it lot better. I'd actually got something I could hang onto. At least I had something to definitely say this person is really ill. I already knew I had a chronic illness. it's just the doctors that wouldn't accept it. I knew whatever was the matter with me wasn't getting any better. And I mean it was just the matter of somebody accepting that I really had a problem.

Some sufferers, however, although relieved, felt that the diagnosis of CFS was sometimes given for lack of a better diagnosis. For others, the diagnosis came as a shock because of its long-term implications and the lack of an effective treatment. At the same time, the uncertainty surrounding the aetiology of CFS was underlined by the choice of a name for the condition. For example, one sufferer said:

The next time I went back [to the doctor] I said: 'Look, I'm really nervous that I've got ME.' And the doctor said: 'Well, we don't find that ME is a useful term to use. We find it rather unhelpful.' I said: 'In that case, what do you call it?' And he said: 'Well, postviral syndrome'. It was a shock. A shock, because I'd assumed that I had something that was going to get better in six weeks. And certainly it seemed that ME could take longer. And yeah, it was pretty awful.

Most sufferers (16) thought the emotional and informational support received from their GPs and/or specialists after CFS had been diagnosed was not adequate, and reported that they felt unsupported and lost:

I am that type of person who puts a lot of faith in professionals like doctors, because I was brought up to respect authority like that. But when I'm left to make the decisions on my own crude information, I find it very difficult. I just wish that my specialist had told me: 'If you follow my advice or my orders . . .' If he had told me: 'You got 9 or 10 years of sheer hell in front of you, unless you do this', I would have listened.

I didn't get any help from the hospital, nothing, absolutely nothing. I became quite critical of the [name of hospital], Dr [name of physician], because he doesn't offer any help at all. I mean at least they could say: 'Get in touch with the self-help group or do this, you know, eat that.'

Other GPs tried to offer some advice, but this was not always appreciated by sufferers, especially if it involved giving up important activities. One mentioned:

My GP said: 'You got to give up work.' I thought I was getting on all right, but he insisted that I gave up, he said I would get worse if I didn't give up. And the consultant said I'd got to come to terms that I'd never get rid of it. I think he wanted me to relax as well. Looking back I think he was just sort of giving me some little bit of hope.

A physician's advice to find psychological or psychiatric support was also not greeted with enthusiasm. For these sufferers, an illness model including maladaptive behaviour was unacceptable and clashed with their own view of CFS as a physical and uncontrollable condition:

I stopped pushing myself. It had become more and more apparent that the more I pushed myself the worse I got. But I couldn't get any medical backup for that point of view. And I've seen several doctors and psychiatric workers and . . . one psychiatric worker who was just disgusting, absolutely disgusting. So I think it's actually put me off the psychiatric point of view.

I felt fine until . . . I went to the hospital and went to see the doctor. And then I realized I was coming up against a brick wall. So I think mostly I have avoided doing that, because I realized it has a bad effect on me. I just felt sort of pushed back on myself. Yeah, I felt an inclination to look at what I'd done wrong.

Such divergent opinions appeared to be associated with the development of extreme anger among sufferers towards doctors and other health professionals who, they were convinced, did not believe that the illness was 'real', were arrogant, and gave them bad advice:

But every time I went [to the doctor] and they'd start asking me about my symptoms . . . I realized there were certain symptoms, if you mentioned them, they sort of behaved really oddly. They'd roll their eyes, look at their students because, you know, [name of hospital] is a big teaching hospital.

At the time I was so depressed because nobody was helping . . . I found it awfully upsetting in the health service, you know, a lot of arrogance and misunderstanding of what I was saying to them. I felt at some point that I was sort of treated as if it was my fault.

Such anger was associated with a general rejection of medical and health professionals and an increased sense of self-reliance among sufferers:

[CFS] taught me not to trust in science, it taught me that the only person I could ever rely on one hundred per cent was myself. I think it led me not to trust doctors as sort of saviours, you know. I felt I was really, really ill this time, and I really wanted some help. I mean I desperately needed help. But there wasn't any there.

Self-reliance was expressed in increased self-management of symptoms, which mostly included organizing the day into resting and active periods, taking vitamins and minerals, and following a diet. Only a few sufferers (5) felt they were treated by understanding general practitioners or specialists. These physicians had prescribed vitamins and minerals and, occasionally, antidepressants.

Choice of complementary and alternative forms of treatment

The lack of perceived support and understanding received from their doctors was associated with sufferers' search for help from non-medical practitioners. Names and addresses of these were usually obtained through self-help groups, which sufferers eagerly joined to increase their understanding of CFS, to obtain information on treatments, and

to obtain emotional support. The desperate circumstances in which some sufferers found themselves led many to try out dubious forms of treatment. Rather than physical help, it appeared that non-conventional treatments frequently offered greater emotional support than those received from general practitioners or specialists. One sufferer, who engaged in acupuncture, described how this helped her to feel better emotionally:

I started out with acupuncture, and I did that for over a year. It gave me a sort of energy boost, and it was quite relaxing. But also, the woman I saw, she was really lovely. She sort of just listened to me . . . I would go and tell her . . . every sort of small symptom I'd had in the entire week. And she sort of listened. And so I got it off my chest . . . I just needed to cry, you know, and have somebody there . . . I mean that was real sort of psychological support.

Although many sufferers hoped that the treatment they engaged in would increase both their physical and emotional well-being, it became obvious that many did not entirely understand some of the treatments they underwent. The following example illustrates this by way of one sufferer's description of the procedure used by a kinesiologist:

It's a system that uses muscle response to test out as well as sort of assessing the information in your body. And he works with mostly vitamin supplements and things. And so he will test out, you know, what's wrong with me. And, I mean, it really did work . . . And I found I sort of had, what he said was I had sort of . . . because of the mercury in my brain, you know, lead from fillings, which I find entirely reasonable. And he had a system for detoxifying the body.

The failure of these treatments to increase physical well-being, however, was associated with repeated attempts at new treatments. Eventually, those long-term sufferers⁹ with experience of several treatments and general experience in managing the illness stopped searching for information about CFS, and reported that they saw themselves as well-informed and that there was nothing new to learn. Several of these sufferers acted as counsellors to newly diagnosed sufferers, providing them with informational support (such as describing their own illness beliefs or suggesting treatments) as well as emotional support:

I have so much knowledge, you know, that I'd like to be able to share. Just from sort of observing so many people's stories . . . I probably know more than the average GP about the cause of the illness.

Thus, rather than relying on doctors or counsellors, experienced sufferers came to the conclusion that only fellow sufferers would be able to provide the necessary support. Interestingly, 4 of the female sufferers intended to train as professional counsellors once 'the illness went away'.

DISCUSSION

Satisfaction with medical support, it seems, is strongly associated with beliefs about CFS, attributions as to its origin, and ways of managing it. Most sufferers believed that CFS is a predominantly physical disease for which increased rest is the most appropriate treatment, but they judged such a belief incompatible with the views expressed by many physicians^{2,4}. This led to disagreements between the sufferers and their physicians and other health professionals, and to dissatisfaction with treatment and the medical establishment as a whole. The result was that they turned away from orthodox medicine.

The unwillingness of the sufferers to accept that psychosocial factors contribute to the aetiology of CFS is common amongst members of the self-help organizations from which they were recruited. These organizations tend to promote a view that downplays the role of psychosocial factors¹⁵. It is noteworthy, therefore, that sufferers in the present investigation did not distinguish between 'wanting to be ill' or malingering and being psychiatrically ill. For example, it was assumed that anybody with depression *wanted* to be ill and taken care of by others. However, most sufferers wrongly distinguished between CFS 'being all in the mind' and physical symptomatology—that is, they assumed that a psychological aetiology precluded fatigue and myalgia, which they regarded as physical symptoms.

Clearly, the uncertainties about the aetiology or chronicity of CFS strongly encourage sufferers to construct their own illness beliefs which may well lead to the adoption of inappropriate coping strategies^{8,18}. Illness beliefs and coping strategies may be related to functioning^{19,20}. Likewise, those same uncertainties create difficulties for clinicians not only in deciding which treatments and coping strategies to recommend¹ but also in adopting a manner that enables the patient to accept them. Members of self-help groups from which the present sample was taken probably represent a distinct subset of CFS sufferers²¹.

Nevertheless, in line with Ley's¹⁶ view of doctor-patient communication, the present results show that sufferers would welcome from their medical practitioners (whom they regard as figures of authority) comprehensive information about aetiology, prognosis, and the effectiveness of treatment. But the results also show that such information may be rejected if it contradicts the sufferer's illness beliefs.

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